



von Hippel-Lindau Disease
THE CURE FOR CANCER IS IN OUR GENES

**ANNUAL ACCOUNTS
ANNUAL CHARITY REPORT
&
INDEPENDENT EXAMINER'S REPORT**

Year Ended 5 April 2024



von Hippel-Lindau Disease
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Receipts and Payments Account (UK) for the Year Ended 5 April 2024

05 April 2023		05 April 2024	
£		£	£
	Receipts:		
7,909	Donations (Inc. Gift Aid)		31,163
-	Fundraising Activities		6,207
201	Trading Activities		630
<u>8,110</u>			<u>38,000</u>
	Payments:		
20,086	Grants and Donations	821	
787	Patient Support	391	
194	Subscriptions	94	
445	Website and Postage	489	
2	Fundraising Charges	105	1,900
<u>21,514</u>			
- 13,404	Net Receipts/-Payments		<u>36,100</u>
48,321	Opening Balance		34,917
- 13,404	Net Receipts/-Payments		<u>36,100</u>
<u>34,917</u>	Closing Balance		<u>71,017</u>
	Represented By:		
	Co-operative Bank		70,017
	PayPal		<u>1,000</u>
			<u>71,017</u>

VHL UK/Ireland Charity is registered in England and Wales (1160381) and Ireland (20101039)



Chair's Annual Report 2023-24

The charity has recovered well from the effects of COVID-19 this year and our donations and fundraising total was a magnificent £37,370. Events included:

- A Charity Ball, in conjunction with Cancer-52, which was incredibly well supported and raised in excess of £6,000 for each of the two charities – our most successful ball yet;
- Events organised by patients and their families, including a Golf Day, sponsored walks, and a sponsored abseil from Wakefield Cathedral!
- VHL Awareness Month in May was very successful this year, raising awareness and funds for the charity with quizzes, cake sales, fashion sales and ad-hoc donations.

There are currently three projects in progress which are being funded by our Grant Awards

- (1) £60,000 VHL patient registry and surveillance project - Genetic Centre at Addenbrooke's, Cambridge under the stewardship of Professor Eamonn Maher.
- (2) £60,000 VHL gene analysis of the 100,000 genome project data - Genetic Centre at Addenbrooke's, Cambridge under the stewardship of Professor Eamonn Maher.
- (3) £20,000 Saturation Genome Editing to Define Genotype/Phenotype Relationships in VHL Disease - specific VHL research work of Professor William Drake at St Bartholomew's Hospital.
- A further £35,000 grant award is currently ring-fenced for a research project at the Crick Institute which we are expecting to release in 2024-25.

The charity continued to work with MSD (Merck) and the National Institute for Health and Care Excellence (NICE) in respect of the approval of NHS funding for the new drug belzutifan (Welireg). The MHRA approval for this drug includes its use for RCC Clear-Cell kidney cancer, hemangioblastomas of the central nervous system and pancreatic neuro-endocrine tumours. The charity is registered as a stakeholder with NICE and continues to be involved in the approval process as a patient expert.

The charity was also involved with the Scottish Medicines Consortium in its appraisal of belzutifan (Welireg) and we were delighted when NHS funding was approved for Scotland in October 2023. Scotland was the first country in Europe to provide funding for NHS patients and this was a huge milestone for the VHL community. It is understood that Wales and Northern Ireland usually follow England's lead. Ireland's patients will be included in the EU process.

Graham Lovitt
Chair

**Report to the Trustees of the
VHL UK/Ireland Charity
Accounts for the Year Ended 5 April 2024**

Respective responsibilities of trustees and examiner

The charity's trustees are responsible for the preparation of the accounts. The charity's trustees consider that an audit is not required for this year under section 144 of the Charities Act 2011 (the Charities Act) and that an independent examination is needed.

It is my responsibility to:

- examine the accounts under section 145 of the Charities Act;
- to follow the procedures laid down in the general Directions given by the Charity Commission under section 145(5)(b) of the Charities Act; and
- to state whether particular matters have come to my attention.

Basis of independent examiner's report

My examination was carried out in accordance with the general Directions given by the Charity Commission. An examination includes a review of the accounting records kept by the charity and a comparison of the accounts presented with those records. It also includes consideration of any unusual items or disclosures in the accounts, and seeking explanations from the trustees concerning any such matters. The procedures undertaken do not provide all the evidence that would be required in an audit, and consequently no opinion is given as to whether the accounts present a 'true and fair view' and the report is limited to those matters set out in the statement below.

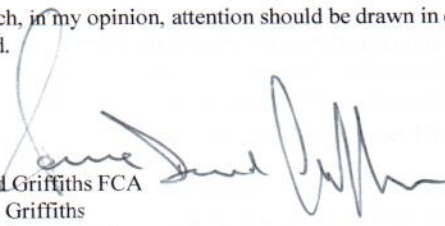
Independent examiner's statement

In connection with my examination, no matter has come to my attention:

(1) which gives me reasonable cause to believe that, in any material respect, the requirements:

- to keep accounting records in accordance with section 130 of the Charities Act; and
- to prepare accounts which accord with the accounting records and comply with the accounting requirements of the Charities Act have not been met; or

(2) to which, in my opinion, attention should be drawn in order to enable a proper understanding of the accounts to be reached.


Paul David Griffiths FCA
Hepworth Griffiths
Chartered Accountants
47 Grove Street
Retford
Nottinghamshire
DN22 6LA

Date:

3/2/2025